



Treatment

Cancer is a complex group of diseases. To further complicate matters, different cancers behave differently and respond to different treatments. Treatment choices depend upon the type and stage of cancer as well as a variety of individual factors that include age, health, cultural and personal preferences. Care is comprised of various services, resources, and technology.

On average, 4,495 new cancer diagnoses are reported annually in Montana and 4,022 cases of cancer are treated annually (Montana Central Tumor 5-year averages, 1999-2003). To effectively improve cancer treatment outcomes, state-of-the-art care must be available, accessible, affordable, and utilized. It is crucial to integrate, coordinate, and maximize treatment services and resources.

While good cancer treatment can be available at the local level, Commission on Cancer (CoC) approval ensures the quality of cancer care through adherence to national standards, multidisciplinary consultation, and quality assessments. Any size facility may be approved as standards are categorized based on the number of cancer patients treated. As of January 2005, four of Montana's medical facilities were CoC approved. In 2003, the most recent year for which a complete set of data is available, 36 percent of Montanans with cancer were treated in CoC approved centers. Nationally, 80 percent of cancer patients are treated in CoC approved facilities.

- Clinical practice guidelines serve as a guide for doctors and outline appropriate methods of cancer treatment, rehabilitation, and follow-up care.
- A system of community health advisors, patient navigation tools, and Cancer Resource Centers would improve use of the complex cancer healthcare system, guide the patient and family, decrease stress, and improve communication.
- Efficient use of treatment services requires that evidence-based information be available to healthcare providers and the public.

We envision comprehensive cancer treatment that meets national standards — available to, and accessible by, all Montanans.

Availability: Montana is the fourth largest state in terms of land mass, encompassing 147,046 square miles, and has just over 900,000 residents. This equates to about six people per square mile, making Montana one of the last remaining frontier states. Lengthy distances between population centers, coupled with a small population, become obstacles to availability, capacity, and consistent state-of-the-art cancer treatment.

Accessibility: Access to state-of-the-art cancer treatment can be limited by a variety of personal, geographical, and cultural barriers. This may include lack of insurance, cost of care, location, lack of transportation, extraneous costs including travel and childcare, as well as other cultural and physical barriers. Cancer patients should have access to all forms of therapy from which they can benefit.

Affordability: Cost may be the biggest barrier to accessibility and optimum cancer treatment. For the 19 percent of Montanans who lack health insurance, cost is overwhelming. Even those who have health insurance may find that their carrier doesn't provide complete coverage.

Utilization: In order to fully utilize state-of-the-art services, cancer patients and their families must be aware of available services. Maximizing utilization means empowering patients and their families by ensuring that they know and understand their options.

First Steps:

- Identify gaps in the availability and types of cancer treatment services.
- Identify barriers to accessibility and utilization of cancer care services, which might include cost, geographic location, cultural factors, uneven distribution of resources, or care choices that lack standardization.

Goal I: Ensure prevailing standards of care for all cancer patients.

Objective I.1: *Increase the percentage of cancer patients given care consistent with national treatment standards.*

Baseline: Thirty-six percent of cancer patients were treated by three CoC-approved programs in 2003

Outcomes: By 2007, determine the percentage of patients whose treatment was consistent with national standards, but who were not treated in CoC-approved programs

By 2011,

- Define treatment barriers
- Define and promote treatment standards and resources
- Increase the number of CoC-approved programs in Montana to six
- Increase the number of patients treated at CoC-approved cancer treatment centers by 25 percent

Data sources: Montana Central Tumor Registry (MCTR) 2002; CoC 2005; provider survey

Strategy 1	Determine the percentage of patients whose treatment was consistent with national standards, but who were not treated in CoC-approved programs.
Strategy 2	Promote visibility of CoC-approved programs by citing accredited programs in cancer treatment materials and promotions.
Strategy 3	Encourage unaccredited centers treating cancers to move to CoC approval status appropriate to their size.
Strategy 4	Support ongoing accreditation of CoC-approved programs.
Strategy 5	<ul style="list-style-type: none">• Educate cancer patients about resources available, treatment options, national treatment standards, rehabilitation, and follow-up guidelines in a cancer-specific format.• Educate healthcare providers about the resources available and promote national cancer treatment standards and evidence-based practices as user-friendly tools that are site and stage specific.
Strategy 6	Identify cancer patients' barriers to engaging in treatment, rehabilitation, and follow-up consistent with national standards. Analyze disparities across population groups (e.g. racial, disability status, geographic, economic). Design and implement strategies to assist patients in overcoming these barriers.
Strategy 7	Promote accredited, professional, cancer-related educational sessions on evidence-based best practices, national standards, guidelines, cost-effective treatment, and follow-up care.
Strategy 8	Support enhanced telemedicine capacity.
Strategy 9	Promote resources and coordination for follow-up care in frontier and American Indian reservation communities.

The National Comprehensive Cancer Network (NCCN) is an alliance working to develop treatment guidelines as tools to guide decision-making in cancer management.

The Commission on Cancer (CoC)

The CoC is a consortium of professional organizations dedicated to reducing the morbidity and mortality of cancer through education, standard-setting, and monitoring the quality of care. Membership is comprised of 100+ representatives of the American College of Surgeons (ACoS) and the 39 national, affiliated professional organizations.

The Commission: sets standards for quality and multidisciplinary cancer care; surveys hospitals; collects quality data with which to measure treatment patterns and outcomes; evaluates hospital provider performance; and develops educational interventions to improve cancer care outcomes at national and local levels.

Goal I: Ensure prevailing standards of care for all cancer patients.

Objective I.2: *Enhance childhood cancer oncology services in Montana.*

Baseline: Data, analysis, and protocols are not available

Outcomes: By 2008,

- Define need for childhood oncology services
- Quantify and define service gaps and disparities
- Create, institute, and promote communication protocols

Data sources: Process evaluation results

Strategy 1	<p>Establish a committee to delineate and analyze data:</p> <ul style="list-style-type: none"> • to determine the need for a pediatric oncologist to provide full- or part-time consultation to childhood cancer patients and their families. • to determine disparities and gaps in childhood cancer services.
Strategy 2	If need is determined, strategize and implement enhancements to childhood cancer services.
Strategy 3	<p>Establish and promote protocols for communication:</p> <ul style="list-style-type: none"> • among local, regional, and tertiary childhood cancer treatment centers. • among medical service providers and parents.



2002

Rylie was just three when she started complaining of a headache. When it didn't let up after a few days, Rylie's mother, Kim, took her to the pediatrician, who attributed the toddler's symptoms to a virus. That was in early June 2002. Four days later, Rylie wasn't better, and they went back to the pediatrician's office. Though he prescribed antibiotics, Rylie remained listless, and began running a low-grade temperature. After a few more days, Kim took Rylie back for the third time. This time, the pediatrician ordered some tests. Kim and Rylie hadn't been home for two hours when the doctor called. "I need you and your husband to come back in, right now."

The doctor was pretty certain that Rylie had leukemia, but said that they'd have to take her to the pediatric oncology center at the Denver Children's Hospital for confirmation. The only option they could afford was to drive her there, so Kim and her mother left the next day, with Rylie in the back seat. The diagnosis came back June 25, and Rylie started intravenous chemotherapy immediately. She stayed in the hospital for a week. After the initial round of chemotherapy, her test results were good. Even so, 17 months of intense chemotherapy followed. Every four months, Rylie and Kim would travel to Denver, then return to Montana for follow-up care.

They thought they were out of the woods, but in November 2003, Rylie started complaining of headaches again. The cancer was now in Rylie's central nervous system, and her best chance lay in an unrelated umbilical cord blood transplant. The Fairview University Medical Center was a pioneer in the field; by then they had done over 6,000 cord blood transplants. March 1, Rylie, Kim, Rylie's dad, Chris, and her brother Ty, arrived in Minneapolis. Rylie went through two months of intensive chemotherapy, a time that Kim remembers as the worst of all. The transplant itself was uneventful, and Rylie did remarkably well. She was up and playing almost immediately.

The good news? Rylie's last day of medication was July 26, 2005, two days before her sixth birthday.



2005

"At first I thought we didn't need other people, that we could handle this ourselves. That just wasn't true. Throughout Rylie's illness, we've received a lot of emotional and financial support from others. The financial support, especially, was hard to accept, but ultimately it taught me that it's okay to accept help. Everyone was so good to us. It seemed that everyone who heard about Rylie wanted to help. If not for the generosity people showed us, we would be telling a completely different story today."— Kim, mother of Rylie, a 6-year-old cancer survivor

Goal II: Promote utilization of appropriate cancer services for childhood cancer patients and their families.

Objective II.1: *Make a list of short-notice travel resources for children diagnosed with cancer and their families.*

Baseline: No resource list is available for distribution

Outcomes: By 2008, make a travel resource list available

Data sources: Process evaluation

Montana children diagnosed with cancer are referred out-of-state to regional cancer centers for initial treatment. Travel becomes a major obstacle for families.

Strategy 1	Compile a list of current resources available for transportation to regional cancer centers, as well as resources providing for in- and out-of-state travel expenses and destination housing options.
Strategy 2	Create and disseminate a travel resource list for newly diagnosed pediatric cancer patients and add to the <i>Cancer Resource Roster</i> on the Cancer Control webpage.
Strategy 3	Identify and improve funding available for transportation and housing for childhood cancer patients and their families.

“Residents of poorer counties, irrespective of race, have higher death rates from cancer. Disparities are caused by the complex interplay of low economic class, culture, and social injustice, with poverty playing the dominant role.”
— Harold Freeman, M.D.

Goal III: Assess and improve availability, accessibility, and timely utilization of cancer treatment services for all populations.

Objective III.1: *Analyze and improve cancer treatment services by geography, ethnicity, socioeconomic level, age, disability, and insurance status.*

Baseline: No clinically based analyses have been identified

Outcomes: By 2008,

- Identify data resources for use in analysis
- Analyze and identify barriers, gaps, and disparities
- Identify public policies that present obstacles to equitable treatment
- Make recommendations for appropriate remediation

Data sources: Process evaluation results

Strategy 1	Identify existing cancer data and analyze for barriers and disparities to availability, accessibility, and utilization by specific factors (e.g., incidence, mortality, outcomes, cost, insurance coverage, readmission rates, treatment choices, types of treatment, resources, and efficiency). If data are unavailable, identify ways to meet data needs.
Strategy 2	Analyze public policy for barriers to treatment.
Strategy 3	Compare Montana's data with national trends to identify significant variations.
Strategy 4	Develop strategies for implementation that will address identified disparities and barriers, and fill service gaps.

Goal III: Assess and improve availability, accessibility, and timely utilization of cancer treatment services for all populations.

Objective III.2: *Reduce economic barriers to quality care for cancer patients.*

Baseline: 4.5 percent of Montana cancer patients are coded “no insurance” in the primary payer field of the MCTR (2001 - 02)

Outcomes: By 2011,

- Reduce the number of Montana cancer patients coded as no insurance to 4 percent
- Ensure that a wide range of assistance is available for the under- and uninsured

Data sources: MCTR; process evaluation results

Strategy 1	Support policies and legislation designed to broaden insurance coverage for diagnostic and treatment services for low income, under- and uninsured cancer patients.
Strategy 2	Support incentives that allow individuals and small businesses to purchase health insurance.
Strategy 3	Support efforts to ensure healthcare providers and staff receive ongoing education regarding low- or no-cost treatment resources.
Strategy 4	Collect the data necessary to: <ul style="list-style-type: none"> • analyze insurance coverage for cancer treatment. • determine the scope and reasons for lack/delay of treatment among diagnosed cancer patients. • identify and implement strategies designed to reduce economic barriers and inequities.
Strategy 5	Support continued funding for the Breast and Cervical Cancer Treatment Program, the Montana Comprehensive Health Association, community health centers, and cancer treatment through the Indian Health Service.
Strategy 6	Support Medicaid reimbursement to healthcare providers at economically viable levels.
Strategy 7	Support expansion of Medicaid and Children’s Health Insurance Program (CHIP) eligibility and benefits to: <ul style="list-style-type: none"> • provide adequate coverage to uninsured cancer patients and their families. • reduce any identified health disparities among racial and ethnic groups, poor, and medically underserved populations. • improve access to cancer care for medically underserved populations. • increase Medicaid and CHIP benefit utilization for adults and children with cancer.
Strategy 8	Work with the Montana State Planning Grant or similar organization on under- and uninsured cancer treatment issues.

Women screened through the Montana Breast and Cervical Health Program may also be eligible for treatment benefits through the Montana Breast and Cervical Cancer Treatment Program.

Objective III.3: *Increase the number of healthcare providers offering their patients help navigating the cancer care system.*

Baseline: A comprehensive cancer treatment resource list is unavailable; there are no American Cancer Society (ACS) Cancer Resource Centers in Montana

Outcomes: By 2008, create a statewide cancer treatment resource list and determine the number of cancer treatment centers and healthcare providers offering patients access to community health advisor navigator programs, self-navigation guides, or resource directories

By 2011,

- Implement Cancer Resource Centers in five locations
- Increase by 20 percent the number of cancer treatment centers and providers that facilitate access to community health advisor navigator programs, self-navigation guides, or resource directories

Data sources: Process evaluation results; provider survey

Strategy 1	By 2008, determine the baseline percentage of cancer treatment centers, tribal health systems, and providers that facilitate access to navigation guides or resource directories for cancer patients and families.
Strategy 2	Compile a list of cancer-related treatment resources in Montana, organized by geography, and update annually. Make the list available to cancer treatment centers, providers, and the interested public.
Strategy 3	Add the treatment resource list to the <i>Cancer Resource Roster</i> on the Cancer Control webpage.
Strategy 4	Analyze resource gaps in availability and barriers to access and utilization; design strategies to improve resource distribution and utilization.
Strategy 5	Promote establishment of evidence-based community health advisors or navigator programs; promote utilization of the programs starting at the time of diagnosis. Encourage cancer treatment center navigator programs to practice outreach to the frontier communities in their referral areas.
Strategy 6	Encourage navigator and resource staff training in clinical and insurance systems, national standards and trends, cost-effective measures, resources, and services.
Strategy 7	Investigate funding to start an ACS Navigator Program in Montana.
Strategy 8	Promote establishment of ACS Cancer Resource Centers; start with cancer treatment centers and expand outreach to referral communities.
Strategy 9	Sponsor distribution of patient self-navigation programs. Consider promoting a cancer-specific checklist to improve cohesion of clinical services.

Montana by the Numbers (2000 Census)

- Montana is a racially homogeneous state: 92.2 percent of the population is White. The largest minority is American Indian, who comprise approximately 7.4 percent of the population.
- 16.9 percent of the population between the ages of 21 - 64 and 39.6 percent of the population aged 65+ have a disability.
- 14.6 percent of the population overall is living in poverty.
- The annual median household income is \$33,024. The annual per capita income is \$17,151.
- Of Montana's 56 counties, 45 qualify for "frontier" status because they have six or fewer people per square mile.

Goal IV: Promote optimum patient/provider communication to improve cancer survivors' experiences as healthcare consumers.

Objective IV.1: *Increase healthcare providers' communication skills with cancer survivors and their families regarding the illness, prognosis, treatment, and follow-up options.*

Baseline: The number of accredited educational courses currently (2006) available to physicians, nurses, pharmacists, and other healthcare professionals that address communication with cancer patients and their loved ones; the number of courses on this topic currently available to, and required of, healthcare students

Outcomes: By 2008, determine the baseline

By 2010, increase by a percentage to be determined the number of accredited educational courses for health care professionals and the number of required courses available to healthcare students on communicating with cancer patients and their loved ones

Data sources: To be determined

Strategy 1	Determine the baseline number of accredited educational courses and required courses available to healthcare professionals and students on the topic of culturally appropriate communication with cancer patients and families.
Strategy 2	Work with appropriate entities to increase the number of courses available in Montana so that each healthcare provider in contact with cancer survivors receives training on the topic at least once every five years.
Strategy 3	Explore incentives to encourage healthcare providers to increase their knowledge and communication skills.

Objective IV.2: *Review, develop, and promote resources for improving patient/provider communication.*

Baseline: Resources currently available to patients on communication with providers

Outcomes: By 2008, delineate the resources available to patients on communication with providers

By 2010, make a communications tool available to all cancer patients

Data sources: Process evaluation results

Strategy 1	By 2008, determine what resources are available to patients on communication with providers.
Strategy 2	Add the patient/provider communication resource list to the <i>Cancer Control Resource Roster</i> on the Cancer Control website and promote it to the public.
Strategy 3	Define the common barriers to patient/provider communication.
Strategy 4	Identify programs or services to assist in overcoming barriers to patient/provider communication. If no effective program exists, develop an effective, comprehensive, culturally competent tool to help patients communicate with their providers.

Treatment: What You Can Do

Be proactive: If you or a family member is diagnosed with cancer, become familiar with treatment options as well as national treatment, rehabilitation, and follow-up guidelines for that cancer. Ask about appropriate lower-cost treatment choices.

Educate yourself: Use the community health advisor, navigator tools, resource centers, and rosters available for cancer patients.

Encourage:

- your healthcare providers to participate in state-of-the-art educational opportunities on cancer diagnosis, treatment, and evidence-based, cost-effective care.
- your local cancer treatment center to pursue size-appropriate Commission on Cancer approval.

Support:

- funding to assist the families of childhood cancer patients with travel.
- participation in Comprehensive Cancer Control projects in your community.
- policies that improve access to quality care for low income and uninsured Montanans.

Utilize:

- the resources available on effective communication to interact with your healthcare provider.

Patients who fully understand the treatment program experience greater satisfaction with their care, and are more likely to complete treatment despite the inevitable side effects.

Rita

McDonald is a colon cancer survivor. “I could have been better informed,” she says. “I

wasn’t told that I should get a screening colonoscopy. I was totally in the dark. That’s why it’s so important to me to get the word out. I want to make a difference — no one should have to go through what I have and the cancer I had is almost 100 percent preventable.”



Rita was experiencing diarrhea and other symptoms, but had written it off to something she’d encountered on a recent vacation. When she went in to see her doctor about it, though, she was immediately sent in for a colonoscopy. Within a week, she was in surgery. Unfortunately, the cancer had already moved into Rita’s lymphatic system, making it much more difficult to treat. Rita says she is thankful that she had symptoms. Colon cancer is often called the “silent killer” because there are often no symptoms until late in the disease.

After her surgery, Rita remembers lying in the hospital thinking that she would make sure everyone she loved knew about this. She promised herself that she would do whatever she could to see that this didn’t happen to any of her family or friends. With Rita’s encouragement, her sister and sister-in-law both had colonoscopies that July. As it turns out, her sister-in-law had colon cancer, and her sister had polyps, which can develop into colon cancer if not removed. Both were caught in time. Rita was lucky, too: January 2005 marked three years of being cancer free.

“This has been a really, really long ordeal. I just want so much to make an impact on people so that they know they don’t have to go through what I’m going through. People need to understand that colon cancer is preventable.” — Rita McDonald